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The achievements of genetic engineering are rapidly expanding in everyday medical practice, as they offer solutions for diseases which have been incurable so far. However, genetic engineering also has disadvantages as it questions everything thought about humans until now, thus transforming the concept of the right of human dignity. This study searches for legal answers to the following questions: (1) how human dignity manifested? (2) in what cases may genetic engineering be harmful?

Keywords

Genetic engineering; human dignity; self-determination; physical integrity; Oviedo Convention; human genetic examinations; life-saving siblings; cloning; pre-implantation examination; human genetic research.

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The achievements of genetic engineering are rapidly expanding in everyday medical practice, as they offer solutions for diseases which have been incurable so far. However, genetic engineering also has disadvantages as it questions everything thought about humans until now, thus transforming the concept of the right of human dignity. This study searches for legal answers to the following questions: (1) how human dignity manifested? (2) in what cases may genetic engineering be harmful?

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I. Introduction

Around 350 BC, Aristotel already supposed that genetical information is transmitted to descendants; about two thousand years later, in 1865, Gregor Mendel discovered these inheriting units [1] (p. 550). Since then, doctors and researchers set high hopes in genetic knowledge and technology, which may lead to curing today's incurable hereditary diseases.

Gene technology does not only modify a human's body and define future generations, but it may also provoke changes in human rights (if people alter themselves, their rights may also be altered). Therefore, the definition of human dignity and its manifestations may change, as with

the help of gene technology, the human body can be altered on the most basic level and with this, the entire mankind.

Whether we have the right to gene alteration is a question that cannot be answered individually. Answering such a question must comply with international standards to which countries comply and which protect human dignity. Furthermore, it is important that human dignity in case of gene editing is protected not only in individual cases, but generally worldwide.

II. The right to human dignity

A. The concept of human dignity

There are two traditional ways of interpreting human dignity. The first tradition explains human dignity as “within the doctrinal framework of the sanctity of human life” [2] (p. 40), in which human life is presented as God’s gift. For the second tradition, human dignity is “justified by the unique abilities of normal people” [2] (p. 41). The latter implies that individuals are able to live their lives on the basis of their own moral rules; in this case, the essence of human dignity is respect.

According to Ludwig Siep, human dignity can mostly be defined in its negative meaning; that is, when human dignity is violated. For example, human dignity can be violated when an individual is seen as an object rather than a subject, but also when people are humiliated and ashamed [3] (p. 5).

B. The legal concept of the right to human dignity

In Judit Sándor’s interpretation, human dignity is considered two-fold: on the one hand, it is the basis for ethical norms, a guiding principle used to define behaviour rules; while on the other hand, it is a fundamental right, included in national constitutional laws as well as in international human rights [4] (p. 47).

According to the first abortion decision of the Hungarian Constitutional Court in 1990, the right to human dignity means that “the autonomy and the self-determination of the individual has a core which prevents the disposal of others; humans are subjects, and they should not become instruments or objects” [5]. Human dignity is untouchable for every human and does not depend on what and how much people have achieved [5].

As “the practice of Hungarian constitutional court assigns the right to human dignity a general function which protects the personality” [6] (p. 104), human dignity is considered a matter of law which can be invoked before court. The right to self-identity, self-determination, and physical integrity can be derived from the general personality protection. Alongside these functions, the right to human dignity protects the equality of people’s lives. The inviolability of the private sector is also protected by the right to human dignity, as the Hungarian Constitutional Court ruled in several decisions [7].

C. The appearance of gene editing in international documents

The Universal Declaration of Human Genome and Rights issued by UNESCO in 1997 rules about human dignity and the human genome in Article A. The Declaration does not just emphasize human dignity in the light of law, but it also presents several obligations for the states with regard to it. It defines the human genome as not only the symbolic inheritance of mankind, but also as the basis for the inherent dignity and diversity of humans. Furthermore, the Declaration (which does not have a binding force) establishes that every human should have their dignity and rights respected regardless of genetic attributes. It also declares that people’s uniqueness and diversity must be respected on the basis of human dignity [8] (Article 1-2). The Declaration protects human diversity and takes a stand against any disadvantageous discrimination (including genetic discrimination) which results in harm of the human dignity [8] (Article 6).

The 2003 International Declaration on Human Genetic Data (also issued by UNESCO) deals especially with the human genetic data, containing rules on its collection, application, and storage. The Human Genetic Data Declaration also refers to the issue of human dignity deeming it as a key standard in the course of any procedure involving human genetic data. Thus human dignity is one of the aims of the Declaration: it combines human dignity with the prohibition of discrimination and stigmatization by stating that human genetic data cannot be used for purposes which would differentiate one person from the other and would thus lead to harming human dignity [9].

The Universal Declaration of Bioethics and Human Rights, published by UNESCO in 2005, states that results in science and research should promote respect for human dignity. It declares that the

absolute goal of science and society should primarily be human interest and well-being [10] (Article 3). Article 10 of the Bioethics Declaration deems that humans are equal in their rights and dignity, thus everybody has the right to fair and equitable treatment. Moreover, Articles 11 and 12 of the Declaration rules that although cultural diversity and pluralism must be considered, it cannot be the basis for harming human dignity and fundamental rights. Also, just like the Declaration on Human Genetic Data, the Declaration highlights that it cannot be interpreted in ways that would come against human dignity [10] (Article 28). When announcing the Declaration, the director-general of UNESCO Koichire Matsuura stated that: “By adopting this Declaration, Member States have solemnly affirmed, for the first time in the history of bioethics, the moral commitment of the international community to respect a certain number of universal principles for humanity in the development and application of science and technology, set forth within a single text” [11].

The Council of Europe issued its first binding document, the Oviedo Convention, in 1997. Judit Sándor thinks that the Convention “takes human dignity as general principle for biomedicine” [4] (p. 32). Thus, the Convention admits in the Preamble that the document was created in order to raise awareness that the improper use of medical science and biology might harm human dignity. The unconcealed purpose of the Convention is to respect human dignity and identity in the field of biology and medicine without distinction [12] (Article 1). It is apparent from the Explanatory Memorandum of the Convention that it only contains general principles, thus the states may decide on a wider protection for the fields of biology and medicine [12] (Article 27). The Memorandum also emphasizes that “the Convention as a whole will provide a common framework for the protection of human rights and human dignity in both longstanding and developing areas concerning the application of biology and medicine” [13] (p. 2). Furthermore, it highlights that human dignity “is at the basis of most of the values emphasised in the Convention” [13] (p. 3). The Convention “also uses the expression ‘human being’ to state the necessity to protect the dignity and identity of all human beings. It was acknowledged that it was a generally accepted principle that human dignity and the identity of the human being had to be respected as soon as life began” [13] (p. 4).

Therefore, it is apparent that all these documents consider human dignity as basic and general principle. The right to human dignity embodies everything which can make humans human (subjects) and which do not degrade humans to an objects. Because of dignity, not only are all people are equal but so is the human genome, which can be harmed if biology or medicine use it wrongfully. Because of this, the freedom of research must be harmonized with human dignity. This is the reason why discrimination and stigmatization on the basis of genetical attributes must be prohibited. Thus, although the Declarations acknowledge the uniqueness and diversity in the human genome, it prohibits that human dignity be harmed because of it.

III. The right to human dignity and genetic engineering

Although genetic engineering can enhance the human body, it can also alter or compromise fundamental values, such as the right to human dignity.

If gene technology spreads and there will be more genetically modified humans than unmodified ones, will the biological concept of humans be transformed? If genetically-modified people will also be considered fully human, will the concept of human dignity need to be changed? Or would the very fact that this change is considered be discriminating between genetically modified humans and genetically unmodified people?

Would we have to legally distinguish people from people? Should genetically modified people enjoy a kind of positive discrimination, and for instance, when going through a job application process, would this fact be positively evaluated? Should we differentiate between the people who are genetically modified because of certain genetical diseases and people modified solely for enhancement? If we acknowledge diversity through genealogy, should we also recognize equality? Can an unmodified person be equal to a modified one, or will a genetically modified person be more worthy?

The declaration of human dignity as guiding principle offers people enough guarantee to freely decide on genetic modification.

IV. Human genetic examinations

Human genetic examinations are meant to reveal expected genetic diseases or dispositions for certain diseases before they develop. However, this knowledge may violate the right to human dignity by giving information on a patient's health, without – in most cases – offering a cure for it. So although a person can learn about their (expected) disease, they can neither prevent nor treat it. This way, their right to self-identity and the self-determination can be violated, as they obtain information they cannot use. In such cases, the law provides the right to non-knowledge, whereby the person in question can decide whether or not the result of the human genetic test be revealed.

A. Pre-implantation examinations and prenatal tests

Pre-implantation examination shows which of the embryos to be implanted suffers from a genetic disorder, while the prenatal test reveals whether the fetus is suffering from a genetic disorder. Although the benefit of preimplantation is that only the most viable embryos are implanted in the mother's body (thus protecting the mother from possible miscarriage), the disadvantage is that in many cases, selection can result a kind of infant design when parents choose between healthy embryos (treating them as objects), based on eye colour and intelligence. Can the right to human dignity of an already born child be violated in the event that the parents have tailored the child to their liking? Does the right to physical integrity also include the right to genetic integrity, and can the right to self-identity also include the right to genetic self-identity?

Discussing the pre-implantation examination, Michael Quante asks himself: "is it philosophically acceptable that we put the incipient human's life under the boundless protection of the guiding principle of the human dignity? Or should we conclude that, in the changed situation of life sciences and medicine, the principle of human dignity should not be applied to all stages of human life?" [2] (p. 47). However, it is important to note that in the case of embryos, it is also arguable whether the principle of progressivity is applicable in regard to the right to human dignity. Two issues should be considered: stating that the embryo is not a human being (as done in many states), and ensuring protection, so that neither research nor surgical interventions can be

carried out without proper ethical considerations. In addition, design interventions could be prevented if the embryo or the foetus is given a conditional human dignity from conception which could help to avoid unnecessary genetic interventions without their knowledge and consent – because in this case, it would not be primarily about parenting, but about having a child with a certain purpose and specific characteristics [14] (p. 209). Furthermore, the baby designing process not only involves treating the child as a thing (and thus violating human dignity), but more healthy embryos could be killed in the process.

B. Life-saving siblings

Both in the United States of America and the United Kingdom (here regulated and only permitted when the procedure fits particular conditions) it is allowed to do pre-implantation examinations on the embryos awaiting implantation in order to find out which embryo genetically suits better as donor.

Since an embryo does not have human dignity, its right to dignity cannot be discussed. However, the self-identity and the right to physical integrity of the child born with the specific goal of serving as donor can be questioned. While the child may help a sibling, they cannot freely agree to the procedure as the first treatments are done when the child is very young. Nevertheless, while it cannot be argued that through the birth of a donor child, two children may live healthy lives, the life-saving sibling procedure does not guarantee to heal the child who is suffering from a genetic disorder. If the procedure is not regulated, the parents may still play the legal system by conceiving a child naturally. If in such a case the prenatal test shows that the foetus will not be a suitable donor for their sibling, the pregnancy can be terminated – thus the life-saving sibling concept is realizable in a quasi legal form.

V. Genetic Engineering

Although genetic surgery is still in its research phase, its application would most likely spread rapidly, as it offers cures for diseases which have so far been considered irreversible. However, such a procedure would jeopardize the right to physical integrity because it interferes with the human body at the most basic level: the intervention modifies or replaces a defective gene. Genetic engineering could thus on the one

hand cure incurable diseases, and on the other hand enhance people's abilities which would not only redefine human dignity, but also the human biological concept.

A. The right to self-determination

The major problem of genetic engineering is that there is no knowledge yet on either its long-term consequences or its side effects. Thus professionals require the permission of their patients in order to apply procedures with no exact information on side effects or consequences. This way, the right to human dignity may be harmed, while the right to self-determination is not actually practiced as the patient agrees to a procedure whose risks are unknown.

The other crucial problem with genetic engineering is that it intervenes on the most basic level, it replaces, modifies, and designs genes. There is still insufficient knowledge as to whether such interventions may lead to gene mutations or to situations when the original disease is cured, but a new disease is developed instead.

B. Enhancement

Genetic surgery does not only aim to cure diseases, but also to enhance people's abilities. However, Siddhartha Mukherjee rightfully asks the following questions: Are we capable to responsibly develop our genes? What could be the consequences of trying to improve the natural information encoded in our genome? Can we make our genomes more "suitable," without risking to make them more unsuitable? [1] (p. 525). Therefore, although scientists would like to intervene in the process of evolution (and speed it up) by procedures which intervene in the human genome, this should be done by knowing the consequences beforehand.

If the goal of genetic surgery is enhancement, would it mean that a person undergoing such a procedure is not "good enough"? Thus is the human dignity not harmed in this case? Furthermore, could the right to human dignity also be harmed if body enhancement is banned? Because, why should people not be able to decide whether they desire sharper vision, better hearing, or particular characteristics? Could legislation prohibit the development of abilities which endanger the life and physical integrity of others, while allowing the development of

other non-harmful abilities? Or should people undergo enhancement procedures if it is not hereditary to descendants (thus leaving the right to self-determination to the descendants)? These are all questions posed by enhancement procedures which are still waiting to be answered.

C. Cloning

There are two types of cloning: reproduction cloning, which is banned in most countries, and therapeutic cloning, whose permissibility is disputed. The Preamble of the first Additional Report of the Oviedo Convention noted that cloning is a practice against human dignity which degrades humans to objects, by creating new humans identical to humans who already exist or have existed in the past. The Report thus banned the intervention [15].

The Fundamental Law of Hungary disposes that human cloning is prohibited [16]. Therefore specialized literature agrees that while therapeutical cloning is permitted in Hungary, reproductive cloning is not [14] (p. 217). “According to certain opinions, as long as the entire human being is not cloned, but only tissue or organs are reproduced, human cloning has not taken place” [17] (p. 120). Some countries allow therapeutic cloning (such as the USA, Sweden, Belgium, South-Korea, or Japan), while other countries have banned all research on human embryos (Ireland, Austria, Poland, Italy or Norway).

Cloning also correlates with human dignity and human equality: “the question may arise on whom would be entitled to be cloned. If cloning will depend on money, it may result in aggravating the inequality of society” [18]. Distinguishing between cloned and un-cloned people could then lead to the violation of human dignity, thus allowing eugenics to fully manifest.

VI. Human genetic research

Human genetic research is controlled both on national levels and international level. As a general rule, the Oviedo Convention permits *in vitro* research in connection to embryos, while it prohibits creating embryos through genetic research [12] (Article 18). The Oviedo Convention states that “scientific research in the field of biology and medicine shall be carried out freely [12] (Article 15). The Convention

does not dispose of the human genetic research so it does not define genetic research.

In spring 2015, the Chinese professor Junjiu Huang announced that he received 86 embryos affected by genetic diseases from clinics which handle artificial inseminations. The research group experimented with the embryos, creating and adding healthy DNAs, but their experiments failed in the sense that the embryos were not healed and died. This is why some believe that the 2015 moratorium by Jennifer Doudna and David Baltimore on the clinical use of gene editing and gene modification techniques in the western world should be abolished, as no state should be left behind in the genetic engineering competition [1] (p. 526-527). This competitiveness is precisely what can endanger the right to human dignity, as it can easily advance the freedom and primacy of science and research, undermining the primacy of people's well-being and dignity. The intentions to modify the human embryo's genome are becoming similar to an intercontinental race [1] (p. 527). The spirit of competition does not always respect human dignity, but it sometimes stands for individual interests, particularly in cases when one would like to match the human genetic research of a very different culture, such as China (which strives to be at the head of human genetic research although it does not yet benefit from the appropriate legal acts and laws).

Human genetic research raises a particular problem: researchers can conduct whatever clinical trials they wish in human embryos. However, the embryos used in research are prohibited to be cropped into human or animal bodies.

Although human genetic research aims to examine the genome, rather than intervening through medical and surgical procedures, it may still hold certain dangers. It may violate the right to human dignity, because it touches the physical integrity of the research subjects – although they voluntarily accepted to be part of the research. The following question arises: did the subjects accept to be part of the research being well informed that they are joining a research whose results are doubtful and which can jeopardize physical integrity and life on the most basic level? Furthermore, another question should be posed: while human genetic research can eliminate the consequences of taking medication (with several exceptions), can it revitalize until then the human genome to its authentic status, during the period when the

serious side-effects occur? As long as researchers do not answer these questions and will have no precise data on side effects and whether they are reversible, a moratorium on human genetic research should be initiated. Until these questions can be answered properly, human genetic research can be regulated by law.

The astronaut twin

Human genetic research can not only be done on Earth, but also in space, as it happened in 2016 with Scott Kelly, who was sent on a 340-day mission on the International Space Station (ISS) in order to research how the human body responds to such long periods in space. Meanwhile, Kelly's twin brother remained on Earth, therefore they both provided a good basis for comparison.

Human genetic research is permitted if the research amounts more benefits than disadvantages for the research subject; furthermore, it is permitted if the research subject's well-being and health has priority over societal and scientific interests [12] (Article 2). Nevertheless, the research could have violated Kelly's right to human dignity as he was locked up in the space station for nearly a year; but as an astronaut, he voluntarily agreed to it. Furthermore, the research could have easily harmed his human dignity as the research did not anticipate what kind of changes the stay on the ISS would produce in Kelly's body.

Although an article claimed that over 7% of his genetic stock was changed as compared to his twin brother, "these stories are biologically impossible. If 7% of Kelly's genome was altered, he would be about as different from a human as a rhesus monkey" [19]. Therefore his gene did not change; only the way it was expressed had changed, but this can be the result of the stressful circumstances he had experienced on the ISS.

VII. Conclusion

Can we interfere in the human genome, although this would imply affecting the lives of future generations without their consent? Is this process not harming the right to human dignity of future generations, given that it would alter their physical integrity on the most basic level? Do we have the right to "determine the next generation's fate, even if it is done with the purpose of improvement?" [14] (p. 204).

The right to human dignity is a reference point in genetic engineering, playing an important role in identifying which treatments can and cannot be performed. However, just stating the right to human dignity may not be enough, as different nations have different understandings of human dignity. Therefore as long as there are no international standards and regulations as to which procedures are allowed and which are not, human dignity can be violated, as different rules can not only increase competition in genetic engineering, but can also create the phenomenon of genetic tourism [20]. “The danger is very real that countries are running a race to be the first, without considering the human rights perspective, bioethical analysis or possible consequences” [21] (p. 9).

References

- [1] S. Mukherjee, *The Gene. An Intimate History*, London: Bodley Head, Vintage, 2016.
- [2] M. Quante, *Menschenwürde und personale Autonomie – Demokratische Werte im Kontext der Lebenswissenschaften*, Frankfurt: Felix Meiner Verlag, 2010.
- [3] L. Siep, “Az emberi méltóság argumentuma az őssejt kutatásról folyó etikai vitában” [The argument of human dignity in the ethical debate on stem cell research], *A személy bioetikai kontextusa* [The bioethical context of the person], Sándor Kőműves and Erzsébet Rózsa, eds., Debrecen: Debreceni Egyetemi Kiadó, 2013.
- [4] J. Sándor, *Az én molekulám – Bioetika és emberi jogok a XXI. század elején* [My molecule – Bioethics and human rights at the beginning of the 21st century], Budapest: L’Harmattan Kiadó, 2016.
- [5] 64/1991. (XII. 17.) AB határozat [Constitutional Court Decision].
- [6] J. Sári, B. Somody, *Alapjogok – Alkotmánytan II* [Fundamental rights – Constitutional doctrine II], Budapest: Osiris Kiadó, 2008.
- [7] “11/2006. (III. 23.) AB határozat” [Constitutional Court Decision] *Magyar Közlöny* [Hungarian Journal], Budapest, no. 32. 2717, 2006
<http://www.kozlonyok.hu/nkonline/MKPDF/hiteles/MK06032.pdf>.
Accessed: April 28th, 2018.
- [8] UNESCO, *The Universal Declaration of Human Genome and Rights*. 1997.
- [9] UNESCO, *The International Declaration on Human Genetic Data.*, Article 7, 2003.
- [10] UNESCO, *The Universal Declaration of Bioethics and Human Rights*, 2005.
- [11] Koichire Matsuura director-general of UNESCO on the occasion of the twelfth session of the International Bioethics Committee, Tokyo, 15

- December 2005.
<http://unesdoc.unesco.org/images/0014/001428/142832e.pdf>. Accessed: April 28th, 2018.
- [12] The Council of Europe, *The Oviedo Convention*, 1997.
- [13] Explanatory Report of the Human Rights and Biomedicine Convention, European Treaty Series, No. 164. <https://rm.coe.int/16800ccde5>. Accessed: April 28th, 2018.
- [14] Z. Navratyil, *A varázsló eltöri pálcáját? A jogi szabályozás vonulata az asszisztált humán reprodukciótól a reprodukatív klónozásig* [Does the wizard break his wand? The regulatory framework from assisted human reproduction to reproductive cloning], Budapest: Gondolat kiadó, 2012.
- [15] The Council of Europe, *The Oviedo Convention's first Additional Report*, Article 1. 1. 1998.
- [16] The Fundamental Law of Hungary, Article III. 3.
- [17] M. Julesz, *Az orvosi jog aktualitásai. Az eutanáziától a klónozásig* [The actualities of medical law. From euthanasia to cloning], Budapest: Medicina Könyvkiadó Zrt., 2016.
- [18] A. O. Homicskó, "Az új technológiák megjelenése az egészségügyben, különösen a géntechnológia és az elektronikus egészségügy" [The emergence of new technologies in health care, in particular genetic engineering and e-health], *Egyes modern technológiák etikai, jogi és szabályozási kihívásai* [Ethical, legal and regulatory challenges of modern technologies], Árpád Olivér Homicskó ed., Budapest: Acta Caroliensia Conventorum Scientiarum Iuridico-Politicarum XXII., 2018.
http://www.kre.hu/ajk/images/doc4/Egyes_modern_techonologiak_etikai_jogi_es_szabalyozasi_kihivasai.pdf. Accessed: April 30th, 2018.
- [19] S. Kaplan, "The truth about astronaut Scott Kelly's viral space genes", *Washington Post*, March 16th 2018.
https://www.washingtonpost.com/news/speaking-of-science/wp/2018/03/16/the-truth-about-astronaut-scott-kellys-viral-space-genes/?noredirect=on&utm_term=.cccdb6141946. Accessed: April 28th, 2018.
- [20] <http://theconversation.com/the-next-frontier-in-reproductive-tourism-genetic-modification-67132>. Accessed: April 28th, 2018.
- [21] P. de Sutter, "The use of new genetic technologies in human beings," *Committee on Social Affairs, Health and Sustainable Development*, April 25th, 2017, <http://website-pace.net/documents/19855/3313570/20170426-recours-nouvelles-technologies-génétiques-EN.pdf/75b25d58-a122-4896-91ae-295d49d42549>. Accessed: April 1st, 2018.